

## **Predicting anxiety and depression among family carers of people with Chronic Obstructive Pulmonary Disease**

Cristina Jácome MSc<sup>1</sup>, Daniela Figueiredo PhD<sup>1,2</sup>, Raquel Gabriel MSc<sup>1,2</sup>, Joana Cruz MSc<sup>3</sup>, Alda Marques PhD<sup>1,2</sup>

1 School of Health Sciences, University of Aveiro (ESSUA), Aveiro, Portugal

2 Unidade de Investigação e Formação sobre Adultos e Idosos (UniFAI), Portugal

3 Department of Health Sciences (SACS), University of Aveiro, Aveiro, Portugal

**Corresponding author:** Daniela Figueiredo, School of Health Sciences, University of Aveiro (ESSUA); Agras do Crasto - Campus Universitário de Santiago, Edifício 30, 3810-193 Aveiro, Portugal; Telephone: 00351 234 372 462; Fax: 00351 234 401 597; E-mail address: [daniela.figueiredo@ua.pt](mailto:daniela.figueiredo@ua.pt)

## **Abstract**

**Background:** Chronic Obstructive Pulmonary Disease (COPD) can be highly incapacitating, imposing a significant burden on family members however, limited research has been conducted on psychological health of family carers. Thus, this study examined anxiety and depression symptoms in family carers of people with COPD and their predictors.

**Methods:** A cross-sectional study was conducted with family carers and respective patients with COPD. The caregiving situation and the perceived burden, through the Carers' Assessment of Difficulties Index, were collected from family carers. Patients' COPD severity and activities limitation were assessed. The Hospital Anxiety and Depression Scale (HADS) was used to assess anxiety and depression symptoms in family carers and patients. Scores  $\geq 8$  were considered clinically significant.

**Results:** A total of 203 family carers ( $58.2 \pm 14.8$  years old; 75.4% female) and respective patients with COPD ( $69.2 \pm 11.5$  years old; 36.5% female) were included. Clinically significant anxiety symptoms ( $\text{HADS-anxiety} \geq 8$ ) were present in 63.5% ( $n=129$ ) of family carers, depression symptoms ( $\text{HADS-depression} \geq 8$ ) in 34% ( $n=69$ ) and both in 27.1% ( $n=55$ ). Perceived burden (odds ratio [OR] 1.04, 95% confidence intervals [CI]=1.01-1.06; 1.05, 95% CI=1.03-1.07) and patients' activities limitation (OR 1.32, 95% CI=1.01-1.79; 1.41, 95% CI=1.01-1.96) were significant predictors of anxiety and depression symptoms. Anxiety symptoms were also predicted by female gender (OR 0.33, 95% CI=0.16-0.66) and depression symptoms by older age (OR 1.03, 95% CI=1.01-1.06).

**Conclusion:** Family carers of patients with COPD experience anxiety and depression symptoms. Perceived burden, female gender, older age and patient's activities limitation were predictors of these distressing symptoms. These findings highlight the need to

## Anxiety and depression in carers of COPD

address family carers' needs, namely by investigating the effectiveness of supportive interventions on family's psychological health.

**Key words:** family carers; COPD; anxiety; depression; psychological health

## Introduction

Chronic Obstructive Pulmonary Disease (COPD) is highly prevalent, especially among older people, and it is projected to be the seventh leading cause of years lived with disability by 2030 (Mathers and Loncar, 2006). At early grades, COPD is characterised by cough, sputum production and breathlessness associated with persistent airflow obstruction. However, as the disease progresses, exacerbations and comorbidities severely affect patients' physical and social dimensions of life (Vestbo et al., 2013). The gradual disability experienced by patients contributes towards the dependence on family members assistance, who become central to provide support (Bergs, 2002). COPD has, therefore, the potential to become highly distressing for both patients and family carers. In recent years, negative impacts on the psychological health of patients with COPD have been described (Qian et al., 2013) however; limited research has been conducted regarding the psychological health of family carers.

The assumption that a caregiving role impacts on family carers' psychological health is well documented for other chronic diseases. In family carers of patients with dementia, cancer or stroke, 40 to 51% experience anxiety (Mitchell et al., 2013, Greenwood and Mackenzie, 2010) and 18 to 33% depression (Mitchell et al., 2013, Grov et al., 2005, Greenwood and Mackenzie, 2010, Berg et al., 2005). The Stress Process Model (Pearlin et al., 1990) is a useful conceptual framework to identify potential predictors of emotional distress among family carers. It helps to understand the complex interaction of the socio-demographic context of care (e.g., age, gender, kin relationship, living arrangements), care demands (e.g., activities of daily living/instrumental activities of daily living dependencies, number of tasks, hours of care), carers' resources (e.g., coping, social support) and carers' outcomes (physical and psychological health) (Pearlin et al., 1990). The model has been largely tested in the context of different

chronic diseases, such as dementia, cancer or stroke and a number of variables have been found to be associated with family carers' psychological distress. The most significant are the female gender (Huang et al., 2009, Kim et al., 2007), the hours spent on caregiving tasks (Sorensen et al., 2006), the kin relationship with the patient (Kim et al., 2007) and patients' functional dependence (Gaugler et al., 2003). These variables are expected to also play a role in the psychological health of family carers of patients with COPD; however, this is still unknown.

Moreover, previous research also suggests that each chronic disease poses distinct caregiving challenges (Molloy et al., 2005). For instance, chronic diseases characterised by cognitive impairments (e.g., Alzheimer's disease) and/or unpredictable courses (e.g., cancer) have been described as more stressful (Kim and Schulz, 2008, Huang et al., 2009). However, COPD specific characteristics, such as the patient's breathlessness and the difficulty in predicting when exacerbations will occur and how they will end, might pose other distinct care demands (Grant et al., 2012). Thus, this study aimed to analyse anxiety and depression symptoms in family carers of people with COPD and to identify their predictor variables.

### Methods

#### Study design and participants

A cross-sectional study with a convenience sample of family carers and respective patients with COPD was conducted. The study received full approval from the Institutional Ethics Committee. The sample was recruited from three primary care centres and one district hospital. Family carers were included if they were the person who provided the largest amount of support to patients diagnosed with COPD according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria (Vestbo et al., 2013). Family carers and patients were included if they were i)  $\geq 18$  years old; ii)

able to understand the purpose of the study and voluntarily consent to participate. Family carers and patients were excluded if one of them i) presented severe psychiatric conditions and/or inability to understand and co-operate or ii) refused to participate. Eligible patients were identified by General Practitioners. The clinic secretaries contacted via telephone all identified patients, explained the purpose of the study, asked about their willingness to participate and to identify their primary family carer. If patients and family carers agreed to participate, they were invited to attend to an arranged meeting in their primary care centre or hospital where researchers informed, both verbally and in a written form, about the study procedures. A total of 266 dyads of family carers and relatives with COPD were contacted and informed about the study, 33 refused to participate as they did not perceive the relevance of the study and 30 failed to attend the meeting. The final sample comprised 203 dyads. All participants were included after signing the informed consent.

### Data collection procedures

Data of family carers and patients were collected in separate rooms. All instruments were administrated in a face-to-face interview conducted by two trained health professionals, a physiotherapist and a gerontologist.

### *Family carers*

Socio-demographic data, namely gender, age, educational level (measured using standardised categories), occupation situation and information on the caregiving situation (kin relationship with the patient, caregiving period and hours of care provided per week) were recorded from family carers. The Portuguese version of the Carers' Assessment of Difficulties Index (CADI) was used to assess carers' perceived burden (Brito, 2002), since burden has been associated with carers' global psychological health outcomes (Savundranayagam et al., 2011). CADI consists of 30 items and for each item,

participants indicate in a 4-point scale if the statement: “does not apply” (0); “applies, but not stressful” (1); “applies and finds it quite stressful” (2); or “applies and finds it very stressful” (3). The total score ranges between 30 and 90 and higher scores indicate greater subjective burden. The Portuguese version of CADI has shown high internal consistency with a Cronbach’s alpha of 0.92 (Brito, 2002). In the present study, similar internal consistency was found (Cronbach’s alpha coefficient of 0.94).

The Portuguese version of the Hospital Anxiety and Depression Scale (HADS) was used to assess anxiety and depression symptoms (Pais-Ribeiro et al., 2007). This scale has good reliability and validity (Snaith, 2003). The HADS contains 14 items, 7 measuring anxiety symptoms (HADS-A) and 7 depression symptoms (HADS-D), which are scored separately (Pais-Ribeiro et al., 2007). Each item has a 4-point response category so the possible scores range from 0 (minimum symptom load) to 21 (maximum symptom load) for HADS-A and for HADS-D. A score  $\geq 8$  in the HADS-A/HADS-D was used to consider the presence of clinically significant anxiety and depression symptoms (Pais-Ribeiro et al., 2007). Cronbach’s alpha coefficients found in the present study, 0.80 for anxiety and 0.71 for depression, were similar to those described by Pais-Ribeiro et al. (2007).

### *Patients*

Patients’ socio-demographic data, lung function, activities limitation resulting from breathlessness and psychological health (HADS) were assessed. A spirometric test, using a portable spirometer (MicroLab 3500, CareFusion, Kent, UK), was performed according to the guidelines of lung function testing (Miller et al., 2005). The COPD severity was classified as early (mild and moderate) or advanced (severe and very severe) in accordance with the GOLD criteria (Vestbo et al., 2013). Activities limitation resulting from breathlessness were assessed by asking patients to select the statement

from the Modified British Medical Research Council questionnaire (mMRC) that best described their respiratory limitation (Vestbo et al., 2013). The questionnaire comprises five grades in a scale from 0 to 4, with higher grades indicating greater perceived respiratory limitation. This scale is simple and valid to characterise the impact that dyspnoea has on activities among patients with COPD (Vestbo et al., 2013).

### Statistical analysis

Descriptive statistics were used to describe the socio-demographic and clinical characteristics of the sample and to examine the frequency of clinically significant anxiety and depression symptoms in family carers and patients. Socio-demographic and caregiving variables of family carers with clinically significant anxiety and depression symptoms (HADS-A/HADS-D $\geq$ 8) were compared with family carers without these symptoms (HADS-A/HADS-D<8) using independent t-tests for normally distributed data, Mann-Whitney U-tests for non-normally distributed data and ordinal data, and Chi-square tests for categorical data. In the case of chi-square tests, when a statistically significant difference was found for a categorical variable with more than two categories, chi-square multiple comparison tests with Bonferroni correction were performed to explore which category(ies) differed from each other. The same statistical tests were performed to compare patients' characteristics between the two groups (family carers with clinically significant anxiety and depression symptoms vs. family carers without these symptoms). The variables that were statistically different ( $p<0.05$ ) between these two groups were used as independent variables in two multivariate logistic regressions using the Enter method. The dependent variable in each multivariate logistic regression was the presence of clinically significant anxiety symptoms (0=absent, 1=present) and the presence of clinically significant depression symptoms (0=absent, 1=present), considering the cut-off of HADS-A/HADS-D $\geq$ 8. The level of



significance considered was 0.05. Statistical analyses were performed using IBM SPSS Statistics version 20.0 (IBM Corporation, Armonk, NY, USA).

## **Results**

### **Participants**

A total of 203 family carers (58.2±14.8 years old; 75.4% female), caring for patients with COPD (69.2±11.5 years old; 36.5% female), were included. Most patients had early COPD (n=137; 67.5%) and 66 (32.5%) advanced COPD. Table 1 provides the sample characteristics.

*(insert table 1 about here)*

### **Psychological health**

The mean anxiety score in family carers was 9±4.5 and mean depression score was 6.4±3.4. Considering a cut-off score  $\geq 8$ , 63.5% (n=129) of family carers had clinically significant anxiety and 34% (n=69) depression symptoms. A total of 55 (27.1%) family carers had both symptoms. Clinically significant anxiety symptoms were present in 52.7% (n=107) of patients, depression in 45.3% (n=92) and both symptoms in 31.5% (n=64).

#### *Carers' psychological health and socio-demographic characteristics*

Anxiety and depression symptoms were more frequent in female carers (chi-square tests  $p=0.001$  and  $p=0.027$ ) and in family carers' with lower educational levels (no education completed, primary school and secondary school; chi square tests  $p=0.010$  and  $p=0.007$ ) (Table 2). Anxiety symptoms were also found to be related with unemployed status (chi-square test  $p=0.011$ ) and depression symptoms with an older age (independent t-test  $p=0.009$ ).

#### *Carers' psychological health and caregiving situation*

## Anxiety and depression in carers of COPD

The presence of anxiety or depression symptoms was not significantly different among the types of kin relationship with the patient (chi-square tests  $p=0.280$  and  $p=0.826$ ) nor with cohabitation (chi-square tests  $p=0.509$  and  $p=0.167$ ) (Table 2). However, both were significantly more frequent in family carers with high subjective burden (Mann-Whitney U-tests  $p=0.001$ ). Depression symptoms were also found to be more frequent in carers providing care for longer periods (chi-square test  $p=0.026$ ) and during more hours per week (chi-square test  $p=0.018$ ) (Table 2).

*(insert table 2 about here)*

### *Carers' psychological health and patients' characteristics*

The frequency of depression symptoms was higher in family carers caring for patients with advanced COPD (chi-square test  $p=0.023$ ) (Table 3). The frequency of anxiety and depression symptoms was also higher in family carers of patients' with greater activities limitation resulting from breathlessness (mMRC) (Mann-Whitney U-tests  $p=0.012$  and  $p=0.001$ ). No statistically significant differences were observed for the other characteristics.

*(insert table 3 about here)*

### Regression Models

Two multivariate logistic regressions were performed to identify the predictors of clinically significant anxiety and depression symptoms (Table 4). Based on the values of odds ratio (OR), if family carers increased in one point the perceived burden, then the odds of developing anxiety ( $HADS-A \geq 8$ ) or depression ( $HADS-D \geq 8$ ) symptoms would be 1.04 (95% confidence intervals [CI]=1.01-1.06) or 1.05 (95% CI=1.03-1.07) times more. If patients' activities limitation (mMRC) increased in one point, the probability of family carers developing anxiety would be 1.32 (95% CI=1.01-1.79) times more and depression 1.41 (95% CI=1.01-1.96). Anxiety symptoms were also predicted by female

gender (OR 0.33; 95% CI=0.16-0.66) and depression by older age (OR 1.03; 95% CI=1.01-1.06). These logistic regression models predicted 20.3% of total variation of anxiety and 24.4% of total variation of depression symptoms.

*(insert table 4 about here)*

### **Discussion**

To the best of our knowledge, this is the first study to analyse anxiety and depression symptoms among family carers of people with all COPD grades and their predictor variables. The main findings were that family carers presented clinically significant anxiety and depression symptoms and their perceived burden, female gender, older age and patient's activities limitation were significant predictors of these distressing symptoms.

The frequencies of anxiety (63.5%) and depression (34%) symptoms in family carers of patients with COPD are in line with those observed in family carers of people with dementia, stroke or cancer (Berg et al., 2005, Covinsky et al., 2003, Grov et al., 2005), highlighting the demanding and stressful nature of the caregiving role in COPD (Pearlin et al., 1990). Statistically significant differences were found for both anxiety and depression symptoms considering gender. Gender was also a significant predictor of anxiety. Research suggests that female carers experience higher levels of physical and emotional stress, subjective burden and lower levels of physical health when compared to male carers (Perz et al., 2011). A number of reasons might explain these differences. Firstly, women and men may perceive the caregiving process differently, i.e., women might see the caregiving role as an unwanted and resented continuation of their life-job, whereas men often perceive caregiving as a new job or meaningful retirement activity (Dupuis et al., 2004). Secondly, compared to men, women tend to use more emotion-focused coping strategies, which are related to higher levels of stress (Matud, 2004).

Thirdly, older male carers tend to receive more formal and informal support compared to female carers. Nevertheless, these gender differences need to be interpreted with caution, since they may not be caregiving-specific, but rather a reflection of the gender differences found in the general population (Altemus, 2006). Low educational levels were also related to a higher frequency of clinically significant anxiety and depression symptoms. This was expected as a high educational level has been shown to be an important contributor to enhance personal resources and use of instrumental coping style (Drageset and Lindstrom, 2005), helping carers to positively cope with the caregiving demands and contributing to their overall well-being.

Contrarily to previous research (Berg et al., 2005, Covinsky et al., 2003), no statistically significant differences were found for both anxiety and depression symptoms considering the kin relationship with the patient. Although spouses have been identified as the highest risk group for distress among all carers (Dupuis et al., 2004), children, particularly adult daughters, are also intensely affected by their caregiving responsibilities. Adult daughters have often to balance several demanding roles at the same time (e.g., spouse, mother, worker, carer, friend), which can lead to high levels of stress and poor psychological health (Brody, 1981). That is why they are often referred to as the “women in the middle” (Brody, 1981). In a recent study with carers of people with different chronic illnesses, the stress burden experienced by spouses and adult children was also equivalent (Savundranayagam et al., 2011).

Anxiety and depression symptoms were predicted by family carers’ subjective burden. These findings are consistent with previous research on family caregiving across other chronic diseases (Carretero et al., 2009, Savundranayagam et al., 2011). Subjective burden, defined as the person’s appraisals of the caregiving situation, have been considered as an important predictor of carers’ psychological health outcomes

(Carretero et al., 2009, Savundranayagam et al., 2011). Family carers who experience higher significant burden often experience poor psychological health, depression, loss of control over the caregiving situation and heavy workload (Perz et al., 2011).

Family carers' psychological distress was also predicted by patient's activities limitation. It is well known that functional decline contributes to the development of carers' subjective burden which, in turn, affects their psychological health (Ng et al., 2009). This is particularly remarkable for depression, since those who were caring for people with advanced COPD presented higher clinically significant depression symptoms. This result was expected since patients at advanced COPD experience a higher degree of physical disability and, thus, an increasing dependence on their family carers. Conversely, no differences on anxiety symptoms between early and advanced COPD were found. This result probably reflects the uncertain and unpredictable nature of the symptoms and the acute exacerbations characteristic of COPD, which are common across the disease course and are one of the most distressing issues faced by families (Boyle, 2009). In this study, however, information on exacerbations was not collected. Since exacerbations may play an important role in carers' psychological health, and specifically in carers' anxiety, future studies should explore if the rate of exacerbations and their characteristics also represent a predictor of carers' psychological distress.

The overall findings suggest that providing care to patients with COPD has a negative impact on family carers' psychological health and that the predictors of carers' psychological distress are in line with those described across cancer, stroke or dementia. Thus, similarly to family carers of these chronic diseases (Selwood et al., 2007), carers of patients with COPD need specific services and supportive interventions (e.g., respite care, psycho-education, mutual support groups) to adjust to their caregiving role.

However, supportive interventions have not yet been investigated in families living with COPD. Pulmonary rehabilitation programs are a recommended standard of care for patients with COPD, combining exercise training with psycho-education (Nici et al., 2006). These programs, although involving an active collaboration among the patient and family (Nici et al., 2006), do not address the needs of family carers directly. Therefore, it would be relevant to develop a psycho-education component integrating the family carers and to analyse its effects on their psychological health and quality of life.

Certain limitations of the present study should be acknowledged. The HADS is a screening tool for symptoms of anxiety and depression and not an instrument to perform a diagnosis of anxiety or depression. Nevertheless, the HADS has shown to be a reliable and frequently used psychological measurement instrument in COPD (Snaith, 2003). This study focussed on the presence of clinically significant anxiety/depression symptoms ( $\text{HADS-A/HADS-D} \geq 8$ ). Future studies could conduct bivariate analysis between absolute values of HADS-A/HADS-D and carers' socio-demographic/caregiving characteristics. This would be a starting point to create multiple linear regression equations to predict the HADS-A and HADS-D scores. Due to the cross-sectional design of the study, the relationship between predictors and psychological distress across the progression of COPD could not be established. Longitudinal designs would clarify these relationships. Another limitation was the lack of a control group since some of the relationships found may not be caregiving-specific. In future studies, a control group with non-carers with similar socio-demographic characteristics should also be included.

## **Conclusion**

## Anxiety and depression in carers of COPD

Family carers of people with COPD experience clinically significant anxiety and depression symptoms and their perceived burden, female gender, older age as well as patient's activities limitation are predictors of these distressing symptoms. These characteristics should be considered in the comprehensive assessment of family carers of people with COPD. Longitudinal studies are, however, needed to analyse the relationship between predictors and psychological distress across the progression of COPD. Future research should address these family carers' needs, particularly through the investigation of the effectiveness of supportive interventions on family's psychological health.

**Conflict of interest:** none.

This work was funded by Portuguese National Funds through FCT - Foundation for Science and Technology in the context of the project RIPD/CIF/109502/2009.

**Description of authors' roles:** DF and AM were responsible for the study conception and design. RG, CJ and JC performed the data collection. CJ performed data analysis and was responsible for drafting the manuscript. DF, RG, CJ, JC and AM critically revised the paper for important intellectual content. AM and DF obtained funding.

**Acknowledgements:** The authors would like to acknowledge all institutions, patients and carers involved for their participation in this research.

## References

- Altemus, M.** (2006). Sex differences in depression and anxiety disorders: potential biological determinants. *Hormones and Behavior*, 50, 534-8.
- Berg, A., Palomäki, H., Lönnqvist, J., Lehtihalmes, M. & Kaste, M.** (2005). Depression Among Caregivers of Stroke Survivors. *Stroke*, 36, 639-643.
- Bergs, D.** (2002). 'The Hidden Client'– women caring for husbands with COPD: their experience of quality of life. *Journal of Clinical Nursing*, 11, 613-621.
- Boyle, A. H.** (2009). An integrative review of the impact of COPD on families. *Southern online journal of nursing research*, 9, 1-12.
- Brito, L.** (2002). *A Saúde Mental dos Prestadores de Cuidados a Familiares Idosos*, Coimbra, Quarteto Editora.
- Brody, E. M.** (1981). "Women in the Middle" and Family Help to Older People. *The Gerontologist*, 21, 471-480.
- Carretero, S., Garcés, J., Ródenas, F. & Sanjosé, V.** (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics*, 49, 74-79.
- Covinsky, K. E., Newcomer, R., Fox, P., Wood, J., Sands, L., Dane, K., et al.** (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine*, 18, 1006-14.
- Drageset, S. & Lindstrom, T. C.** (2005). Coping with a possible breast cancer diagnosis: demographic factors and social support. *Journal of Advanced Nursing*, 51, 217-26.
- Dupuis, S. L., Epp, T. & Smale, B.** (2004). *Caregivers of persons with dementia: Roles, experiences, supports, and coping.*, Ontario, University of Waterloo.



- Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M. A., Townsend, A. & Greene, R.** (2003). Adult day service use and reductions in caregiving hours: effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18, 55-62.
- Grant, M., Cavanagh, A. & Yorke, J.** (2012). The impact of caring for those with chronic obstructive pulmonary disease (COPD) on carers' psychological well-being: A narrative review. *International Journal of Nursing Studies*, 49, 1459-1471.
- Greenwood, N. & Mackenzie, A.** (2010). An exploratory study of anxiety in carers of stroke survivors. *Journal of Clinical Nursing*, 19, 2032-8.
- Grov, E. K., Dahl, A. A., Moum, T. & Fosså, S. D.** (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology*, 16, 1185-1191.
- Huang, C. Y., Sousa, V. D., Perng, S. J., Hwang, M. Y., Tsai, C. C., Huang, M. H., et al.** (2009). Stressors, social support, depressive symptoms and general health status of Taiwanese caregivers of persons with stroke or Alzheimer's disease. *Journal of Clinical Nursing*, 18, 502-11.
- Kim, Y., Baker, F. & Spillers, R. L.** (2007). Cancer caregivers' quality of life: effects of gender, relationship, and appraisal. *The Journal of Pain and Symptom Management*, 34, 294-304.
- Kim, Y. & Schulz, R.** (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20, 483-503.
- Mathers, C. D. & Loncar, D.** (2006). Projections of Global Mortality and Burden of Disease from 2002 to 2030. *PLoS Medicine*, 3, 2011-2030.

- Matud, M. P.** (2004). Gender differences in stress and coping styles. *Personality and Individual Differences*, 37, 1401-1415.
- Miller, M. R., Hankinson, J., Brusasco, V., Burgos, F., Casaburi, R., Coates, A., et al.** (2005). Standardisation of spirometry. *European Respiratory Journal*, 26, 319-338.
- Mitchell, A. J., Ferguson, D. W., Gill, J., Paul, J. & Symonds, P.** (2013). Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *The Lancet Oncology*, 14, 721-732.
- Molloy, G. J., Johnston, D. W. & Witham, M. D.** (2005). Family caregiving and congestive heart failure. Review and analysis. *European Journal of Heart Failure*, 7, 592-603.
- Ng, T. P., Niti, M., Fones, C., Yap, K. B. & Tan, W. C.** (2009). Co-morbid association of depression and COPD: a population-based study. *Respiratory Medicine*, 103, 895-901.
- Nici, L., Donner, C., Wouters, E., Zuwallack, R., Ambrosino, N., Bourbeau, J., et al.** (2006). American Thoracic Society/European Respiratory Society Statement on Pulmonary Rehabilitation. *American Journal of Respiratory and Critical Care Medicine*, 173, 1390-1413.
- Pais-Ribeiro, J., Silva, I., Ferreira, T., Martins, A., Meneses, R. & Baltar, M.** (2007). Validation study of a Portuguese version of the Hospital Anxiety and Depression Scale. *Psychology Health & Medicine*, 12, 225-237.
- Pearlin, L. I., Mullan, J. T., Semple, S. J. & Skaff, M. M.** (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30, 583-94.

- Perz, J., Ussher, J. M., Butow, P. & Wain, G.** (2011). Gender differences in cancer carer psychological distress: an analysis of moderators and mediators. *European Journal of Cancer Care*, 20, 610-619.
- Qian, J., Simoni-Wastila, L., Rattinger, G. B., Zuckerman, I. H., Lehmann, S., Wei, Y. J., et al.** (2013). Association between depression and maintenance medication adherence among Medicare beneficiaries with chronic obstructive pulmonary disease. *International Journal of Geriatric Psychiatry*, 29, 49-57.
- Savundranayagam, M. Y., Montgomery, R. J. V. & Kosloski, K.** (2011). A Dimensional Analysis of Caregiver Burden Among Spouses and Adult Children. *The Gerontologist*, 51, 321-331.
- Selwood, A., Johnston, K., Katona, C., Lyketsos, C. & Livingston, G.** (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101, 75-89.
- Snaith, R. P.** (2003). The Hospital Anxiety And Depression Scale. *Health and Quality of Life Outcomes*, 29, 1-4.
- Sorensen, S., Duberstein, P., Gill, D. & Pinquart, M.** (2006). Dementia care: mental health effects, intervention strategies, and clinical implications. *The Lancet Neurology*, 5, 961-73.
- Vestbo, J., Hurd, S. S., Agustí, A. G., Jones, P. W., Vogelmeier, C., Anzueto, A., et al.** (2013). Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. *American Journal of Respiratory and Critical Care Medicine*, 187, 347-365.

**Table legends**

Table 1 - Characteristics of the sample.

Table 2 – Psychological health of family carers and socio-demographic/caregiving characteristics (n=203).

Table 3 – Psychological health of family carers and patients' characteristics (n=203).

Table 4 - Models explaining anxiety or depression symptoms as dependent variables and carers' perceived burden, gender, age, and patients' activities limitation as independent variables, using multiple logistic regression analysis with the Enter method. (n=203).

## Anxiety and depression in carers of COPD

Table 1 - Characteristics of the sample.

Characteristics	Family carers (n=203)	Patients (n=203)
Age (years) M±SD	58.2 ± 14.8	69.2 ± 11.5
Female n (%)	153 (75.4%)	74 (36.5%)
Educational level n (%)		
No education completed	6 (3.0%)	22 (10.8%)
Primary school	88 (43.3%)	116 (57.2%)
Secondary school	59 (29.1%)	52 (25.6%)
High school/University	50 (24.6%)	13 (6.4%)
Current occupation n (%)		
Retired	99 (48.8%)	159 (78.3%)
Employed	62 (30.5%)	28 (13.8%)
Unemployed	42 (20.7%)	16 (7.9%)
Kin relationship with the patient n (%)		
Spouse	123 (60.6%)	
Son/Daughter	54 (26.6%)	
Brother/Sister	9 (4.4%)	
Other	17 (8.4%)	
Cohabitation n (%)		
Yes	152 (74.9%)	
No	51 (25.1%)	
Caregiving period (years) n (%)		
≤2	40 (19.7%)	
>2	163 (80.3%)	
Caregiving hours per week n (%)		
≤20 hours	127 (62.6%)	
>20 hours	76 (37.4%)	
COPD severity n (%)		
Early		137 (67.5%)
Advanced		66 (32.5%)
mMRC, Median [IQR]		3 [2, 4]

Abbreviations: COPD, Chronic Obstructive Pulmonary Disease; M, mean; IQR, interquartile range;

mMRC, the Modified British Medical Research Council questionnaire; SD, standard deviation.

## Anxiety and depression in carers of COPD

Table 2 – Psychological health of family carers and socio-demographic/caregiving characteristics (n=203).

Socio-demographic characteristics	Family carers		p-value	Family carers		p-value
	Not anxious (HADS-A<8; n=74)	Anxious (HADS-A≥8; n=129)		Not depressed (HADS-D<8; n=134)	Depressed (HADS-D≥8; n=69)	
Age (years) M±SD	58.3 ± 17.3	58.2 ± 13.1	0.964*	56.5 ± 16.1	61.6 ± 11.2	0.009*
Gender n (%)						
Female	44 (59.5%)	109 (84.5%)	0.001‡	95 (70.9%)	58 (84.1%)	0.027‡
Male	30 (40.5%)	20 (15.5%)		39 (29.1%)	11 (15.9%)	
Educational level n (%)						
No education completed	0	6 (4.7%)	0.010‡	2 (1.5%)	4 (5.8%)	0.007‡
Primary school	29 (39.2%)	59 (45.7%)		56 (41.8%)	32 (46.4%)	
Secondary school	18 (24.3%)	41 (31.8%)		34 (25.4%)	25 (36.2%)	
High school/University	27 (36.5%)	23 (17.8%)		42 (31.3%)	8 (11.6%)	
Current occupation n (%)						
Retired	42 (56.8%)	57 (44.2%)	0.011‡	63 (47%)	36 (52.2%)	0.612‡
Employed	25 (33.8%)	37 (28.7%)		44 (32.8%)	18 (26.1%)	
Unemployed	7 (9.4%)	35 (27.1%)		27 (20.2%)	15 (21.7%)	
Kin relationship with the patient n (%)						
Spouse	42 (56.8%)	81 (62.8%)	0.280‡	76 (56.7%)	47 (68.1%)	0.826‡
Son/Daughter	19 (25.7%)	35 (27.1%)		38 (28.4%)	14 (20.3%)	
Brother/Sister	4 (5.4%)	5 (3.9%)		6 (4.5%)	3 (4.3%)	
Other	9 (12.1%)	8 (6.2%)		14 (10.4%)	5 (7.3%)	
Cohabitation n (%)						
Yes	55 (74.3%)	97 (75.2%)	0.509‡	97 (72.4%)	55 (79.7%)	0.167‡
No	19 (25.7%)	32 (24.8%)		37 (27.6%)	14 (20.3%)	
Caregiving period (years) n (%)						
≤2	16 (21.6%)	24 (18.6%)	0.365‡	32 (23.9%)	8 (11.6%)	0.026‡
>2	58 (78.4%)	105 (81.4%)		102 (76.1%)	61 (88.4%)	
Caregiving hours per week n (%)						
≤20 hours	46 (22.2%)	81 (62.8%)	0.549‡	92 (68.7%)	36 (52.2%)	0.018‡
>20 hours	28 (37.8%)	48 (37.2%)		42 (31.3%)	33 (47.8%)	
CADI, Median [IQR]	6 [2, 15]	14 [4.5, 32]	0.001†	6 [2, 16]	20 [9, 37.5]	0.001†

\*, independent t-tests; ‡, Chi-square tests; †, Mann-Whitney U-tests. Abbreviations: CADI, Carers'

Assessment of Difficulties Index; HADS-A, Hospital Anxiety and Depression Scale – Anxiety; HADS-D, Hospital Anxiety and Depression Scale - Depression; IQR, interquartile range; M, mean; SD, standard deviation.

## Anxiety and depression in carers of COPD

Table 3 - Psychological health of family carers and patients' characteristics.

Patients' characteristics	Family carers		p-value	Family carers		p-value
	Not anxious (HADS-A<8; n=74)	Anxious (HADS-A≥8; n=129)		Not depressed (HADS-D<8; n=134)	Depressed (HADS-D≥8; n=69)	
COPD severity, n (%)						
Early	51 (68.9%)	86 (66.7%)	0.463 <sup>‡</sup>	97 (72.4%)	40 (58%)	0.023 <sup>‡</sup>
Advanced	23 (31.1%)	42 (32.6%)		36 (26.9%)	29 (42%)	
mMRC, Median [IQR]	3 [2, 3]	3 [2, 4]	0.012 <sup>†</sup>	3 [2, 3]	3 [2.5, 4]	0.001 <sup>†</sup>
Anxiety, n (%)						
Yes (HADS-A≥8)	38 (51.4%)	69 (53.5%)	0.441 <sup>‡</sup>	79 (59.0%)	28 (40.6%)	0.070 <sup>‡</sup>
No (HADS-A<8)	36 (48.6%)	60 (46.5%)		55 (41.0%)	41 (59.4%)	
Depression, n (%)						
Yes (HADS-D≥8)	31 (41.9%)	61 (47.3%)	0.276 <sup>‡</sup>	55 (41.0%)	37 (53.6%)	0.060 <sup>‡</sup>
No (HADS-D<8)	43 (58.1%)	68 (52.7%)		79 (59.0%)	32 (46.4%)	

<sup>†</sup>, Mann-Whitney U-tests; <sup>‡</sup>, Chi-square tests. Abbreviations: COPD, Chronic Obstructive Pulmonary

Disease; HADS-A, Hospital Anxiety and Depression Scale – Anxiety; HADS-D, Hospital Anxiety and

Depression Scale - Depression; IQR, interquartile range; mMRC, the Modified British Medical Research

Council questionnaire.

## Anxiety and depression in carers of COPD

Table 4 - Models explaining anxiety or depression symptoms as dependent variables and carers' perceived burden, gender, age, and patients' activities limitation as independent variables, using multiple logistic regression analysis with the Enter method. (n=203).

Characteristics	Anxiety (HADS-A $\geq$ 8)		Depression (HADS-D $\geq$ 8)	
	OR (95% CI)	p-value	OR (95% CI)	p-value
CADI	1.04 (1.01-1.06)	0.006	1.05 (1.03-1.07)	0.001
mMRC	1.32 (1.01-1.79)	0.043	1.41 (1.01-1.96)	0.045
Gender (0=male, 1=female)	0.33 (0.16-0.66)	0.002		
Age			1.03 (1.01-1.06)	0.019
R <sup>2</sup>	20.3%		24.4%	

Abbreviations: 95% CI, 95% confidence interval; CADI, Carers' Assessment of Difficulties Index; mMRC, Modified British Medical Research Council questionnaire; OR, odds ratio; R<sup>2</sup>, Nagelkerke R Square.